

Transition from child to adult services for people with xeroderma pigmentosum

This leaflet will explain what transition is, how you will be involved in the process, and what will happen in the transition and adult clinics. If you have any further questions after reading this leaflet, please speak to a doctor or nurse caring for you.

What is transition in xeroderma pigmentosum (XP)?

Transition is the planned and supported move of your care from the children's XP service to the adult XP service.

Because you have XP, you will continue to be reviewed as an adult. It is important that you understand what this means and that you prepare for this. The XP medical team will discuss with you the key issues of your ongoing care as an adult with XP. This will help you to be prepared and ready for the move to the adult XP clinic.

The XP clinical nurse specialists will be the key people to help you and your family work out your health care goals, and what services you may need in order to reach them.

What exactly will happen to me?

Each family takes a different approach to how much you, as a young person, are involved in taking care of your health. This changes as you get older. We want to make sure that when it is time to move on to the adult service, you and your family feel confident to do this.

Many of the doctors and nurses in the adult service are the same as those who cared for you in the children's service, but there will be slight differences. These will be discussed with you. We are here to support you and your family all the way.

Being an adolescent is an exciting time in your life with many changes. You will be entering secondary school and starting to take on more responsibility in many areas of your life. This is also an important time to take more responsibility for your health.

Changes in other areas of your life happen gradually to turn you into an adult. Likewise, transition takes time and the transition clinic will gradually prepare you for the adult clinic.

To start with, we will assess your needs. This will help us to understand how best to support you. This can begin as early as 12 to 13 years old, but remember, this is only the start of the process.

We will use a questionnaire, which you can complete either on your own or with the help of your parent/guardian or specialist nurse.

The questionnaire will ask you about:

- your knowledge of XP and its treatment
- how well you remember, without your parents' help, things like your appointments and taking medicines
- whether you can confidently ask questions about and discuss your health issues with your doctors and nurses
- whether you feel ready to go to the adult clinic when the time comes.

Assessment stages

Stage 1

At 12 to 13 years, we introduce you and your family to the idea of transition.

Stage 2

At 14 to 15 years, we aim to help you understand your type of XP better, what you can do to help yourself, as well as how transition works. We do this by talking about it in more detail.

Stage 3

At 16 to 17 years, we hope that you understand XP, what you can do to help yourself and where to find help if needed.

The transition clinic

Between 16 and 17 years old, you will be invited to the transition clinic. You and your family will have the opportunity to meet both the adult and children's XP teams together in one clinic. Many of these staff will be people that you already know. The transition clinic takes place in the Rare Disease Centre at St Thomas' Hospital. We will send you the appointment details when the time comes. You can attend this clinic either alone or with your family or a friend until you feel confident to go to the adult clinic on your own.

What happens in the adult XP clinic?

The adult XP clinic is held in the same place, with the same doctors and nurses, so there will always be familiar people around you.

Again, you will be offered appointments to see all members of the XP team on the same day. We will also continue to speak with your local health services.

The XP specialist nurse for adults will be able to visit and talk to your college/university or workplace if needed. This is to try and ensure that you are getting all the support that you need.

Sources of useful information

Here are some websites that you may find useful:

w: www.youthhealthtalk.org

XP Support Group – offers advice and practical help for anyone affected by XP.

t: 01494 890 981 **e:** info@xpsupportgroup.org.uk **w:** www.xpsupportgroup.org.uk

Teddington Trust – offers advice and practical help for anyone affected by XP

t: 01233 645 360 **e:** support@teddingtontrust.com **w:** www.teddingtontrust.com

Contact details

If you have any questions or concerns about XP, please contact the XP nurse specialists, **t:** 020 7188 6339 or 020 7188 6351, Monday to Friday, 9am to 5pm. Out of hours, please leave a message on the answer phone with your contact details and someone will call you back within 24 hours.

Guy's and St Thomas' website – useful information, including our patient leaflets.

w: www.gstt.nhs.uk/xp

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch.

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

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